



THE UNIVERSITY *of* EDINBURGH

## Edinburgh Research Explorer

### **Co-production of a pictorial recovery tool for people with psycho-social disability informed by a participatory action research approach—a qualitative study set in India**

**Citation for published version:**

Mathias, K, Pillai, P, Gaitonde, R, Shelly, K & Jain, S 2020, 'Co-production of a pictorial recovery tool for people with psycho-social disability informed by a participatory action research approach—a qualitative study set in India', *Health Promotion International*, vol. 35, no. 3, pp. 486-499.  
<https://doi.org/10.1093/heapro/daz043>

**Digital Object Identifier (DOI):**

[10.1093/heapro/daz043](https://doi.org/10.1093/heapro/daz043)

**Link:**

[Link to publication record in Edinburgh Research Explorer](#)

**Document Version:**

Peer reviewed version

**Published In:**

Health Promotion International

**Publisher Rights Statement:**

This is a pre-copyedited, author-produced version of an article accepted for publication in Health Promotion International following peer review. The version of record Kaaren Mathias, Pooja Pillai, Rakhal Gaitonde, Kakul Shelly, Sumeet Jain, Co-production of a pictorial recovery tool for people with psycho-social disability informed by a participatory action research approach—a qualitative study set in India, Health Promotion International, Volume 35, Issue 3, June 2020, Pages 486–499 is available online at: <https://doi.org/10.1093/heapro/daz043>

**General rights**

Copyright for the publications made accessible via the Edinburgh Research Explorer is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

**Take down policy**

The University of Edinburgh has made every reasonable effort to ensure that Edinburgh Research Explorer content complies with UK legislation. If you believe that the public display of this file breaches copyright please contact [openaccess@ed.ac.uk](mailto:openaccess@ed.ac.uk) providing details, and we will remove access to the work immediately and investigate your claim.



## **TITLE PAGE**

**Co-production of a pictorial recovery tool for people with psycho-social disability informed by a participatory action research approach – a qualitative study set in India**

## **ABSTRACT**

Mental health problems are recognised as a leading cause of disability and have seen increased allocations of resources and services globally. There is a growing call for solutions supporting global mental health and recovery to be locally relevant and built on the knowledge and skills of people with mental health problems, particularly in low income countries. Set in Dehradun district, North India, this study aimed to describe firstly, the process of co-production of a visual tool to support recovery for people affected by psycho-social disability; secondly, the key outputs developed and thirdly, critical reflection on the process and outputs.

The developmental process consisted of participatory action research and qualitative methods conducted by a team of action researchers and an experts by experience (EBE) group of community members. The team generated eight domains for recovery under three meta-domains of normalcy, belonging and contributing and the ensuing recovery tool developed pictures of activities for each domain. Challenges to using a participatory and emancipatory process were addressed by working with a mentor experienced in participatory methods, and by allocating time to concurrent critical reflection on power relationships.

Findings underline the important contribution of an EBE group demonstrating their sophisticated and locally valid constructions of recovery and the need for an honest and critically reflective process in all co-productive initiatives. This study generated local conversations around recovery that helped knowledge

flow from bottom-to- top and proposes that the grass-root experiences of participants in a disadvantaged environment are needed for meaningful social and health policy responses.

## **Introduction**

Mental disorders have been reported as contributing 11.8% of the total burden of disease in India (Patel, Chatterji et al. 2011) yet less than 1% of the national health budget is allocated to mental health service provision (World Health Organisation 2011). The Global Mental Health Movement launched in 2007 (Lancet Global Mental Health group 2007), built on a public health approach grounded in bio-medicine, made a prominent call for resources to increase access to mental health care. This attention to mental health is badly needed, though emerging voices from social scientists suggest we must give greater priority to the political, economic, and social determinants of mental health, community resources and local solutions, and balance the prevailing biomedical approach (Campbell and Burgess 2012, Kirmayer and Pedersen 2014, Jain and Orr 2016).

One potentially powerful response to the lack of focus on social determinants of health and biomedical frameworks is the recovery approach (Slade, Leamy et al. 2012). Recovery is a term that is utilized broadly in the mental health field, with its application to date largely focussed on remission of symptoms and a return to previous employment and roles (Slade, Leamy et al. 2012). However, mental health service users have suggested recovery is a 'way of living a satisfying, hopeful, and contributing life even within the limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness' (Anthony 1993).

Within the field of global mental health, there have been calls to ensure bottom-up, service user driven approaches to recovery, thus ensuring the cultural and social validity of services (Aldersey, Adeponle et al. 2017)

Recovery is also an approach of learning from people in recovery about ‘what works’ and also refers to the broader recovery movement, a values- based endeavour by people in recovery, practitioners and others to transform and develop mental healthcare and services (Roberts and Boardman 2013).

Supporting this approach, recovery ‘tools’ such as the Illness management and recovery program (Mueser, Corrigan et al. 2002) and Wellness recovery action planning (WRAP) (Cook, Copeland et al. 2010) have been evaluated empirically to show improvement in symptoms, hope and quality of life (Slade, Amering et al. 2014).

In India, some mental health professionals have adopted recovery frameworks constructed in Europe and North America, yet recovery approaches as a first step need to reflect the local cultural context and identify local concepts of ‘recovery’, to allow a shared understanding of what recovery is and how it is ‘practiced’ in that place (Gopal and Henderson 2015, Bayetti, Jadhav et al. 2016). Indian studies have identified the importance of community resources such as temple healing (Raguram, Venkateswaran et al. 2002), knowledge and inclusive attitudes (Shidhaye and Kermode 2013) and caregiver perspectives on

recovery (Janardhana, Ragheendra et al. 2018), and have called for a greater emphasis on recovery (Chaturvedi and Thirthalli 2015, Agarwal and Sinha 2016). However, there remains a large challenge in developing vernacular concepts of recovery contextually valid in India in the community (Gopal and Henderson 2015, Bayetti, Jadhav et al. 2016, Janardhana, Ragheendra et al. 2018) and that build on frameworks of clinically applied anthropology among mental health professionals (Jadhav 2013).

A key component of locally and contextually valid approaches to recovery requires a knowledge production model that strongly represents the perspectives of ‘experts by experience’ (EBE) (traditionally on the receiving end of medical research). Growing numbers of publications have demonstrated the value of a co-production process that collaboratively builds on the knowledge of EBE ‘with the knowledge of health or science professionals, and thus honour the right of people to participate in any knowledge creation that ultimately affects their lives (Ottmann, Laragy et al. 2011, Gillard, Simons et al. 2012, Loewenson, Laurell et al. 2014). Benefits of co-production include improved quality and responsiveness of services, more effective and cost-efficient services, strengthened social capital and citizenship (Ottmann, Laragy et al. 2011) and further, space for dialogue between service users and service providers which can increase the possibility for critique of bio-medical discourses which have dominated interventions for the last century (Gillard, Simons et al. 2012).

There is growing recognition that psycho-social interventions in particular, are more likely to be effective where people are engaged in developing and implementing the intervention (Greenhalgh 2009, Ruggeri and Tansella 2013). A further extension of the co-production process is participatory action research which seeks to transform power relationships inherent in the research process. PAR builds on the idea that participation in the research process is a continuum that can range from compliant participation to a research process that can ‘free’ participants from traditional power relations and hierarchical structures, meaning that the research process itself can be ‘emancipatory’ (Loewenson, Laurell et al. 2014). This can offer an alternate model to hierarchies built on identity axes such as caste, age, gender and disability (Nayar 2007, Mehrotra 2012, Jadhav, Mosse et al. 2016). As these hierarchies and their associated mechanisms of social exclusion are of themselves determinants of mental ill-health, PAR is a potentially health -promoting methodology in this setting (Chung and Lounsbury 2006). The core idea of the participatory approach to research is that, “knowledge is built out of the collective comparison of subjective experiences of reality by groups of people commonly exposed to, acting on, and / or with first-hand experience of that reality” (Loewenson, Laurell et al. 2014). This participatory process can thus honour the right of people to participate in any knowledge creation that ultimately affects their lives (Greenhalgh 2009, Ottmann, Laragy et al. 2011, Loewenson, Laurell et al. 2014).



Northern India, with a Hindi speaking population of 650 million, has a poorly resourced and largely ineffective public health system, which has particularly limited access to care for people with psycho-social disability (PPSD)(Patel, Parikh et al. 2015). Implementation of India's National Mental Health Programme typically depends on a psychiatrist who operates out of a district hospital with visits to rural health centres for out-patient clinics. This programme has been criticized as ineffective in engaging communities around mental health due to its biomedical orientation (Jain and Jadhav 2008) and includes very limited psycho-social interventions which are emphasised as central to effective care in global mental health practice guidelines such as the World Health Organisations' mhGap 2.0 publication(World Health Organisation 2016). The Department of Empowerment of persons with disability, within the national Ministry of social justice and empowerment is the Government of India body charged with supporting skill building and community-based rehabilitation (including psycho-social support) for people with disabilities. These services are currently primarily available in larger metropolitan cities although there are plans to expand their reach (Ministry of social justice and empowerment 2018). To our knowledge, there have been few accounts of locally developed tools or resources for 'recovery' co-produced with PPSD and carers, developed in India (Lloyd, Jain et al. 2016). In this paper we build on a framework of health

systems research (Loewenson, Laurell et al. 2014), with a focus on recovery in the field of global mental health, for which we used participatory processes (PAR) and report here on the co-productive aspect.

In this paper, we aim to: a) describe how a participatory action research (PAR) approach was used to guide the process of co-production of a pictorial tool to support recovery for people with psycho-social disability and carers; b) describe the key outputs (recovery tool domains and components) developed through this process; and c) critically reflect on both the process and the outputs with respect to the psycho-social context, power relations and constructions of recovery that emerge.

## **Methods**

### ***Setting***

This study was set in the busy, green valley of Dehradun, which has two million inhabitants and is part of the north Indian state of Uttarakhand. At the time of this study implementation of the National mental health programme had not started and there were six Government psychiatrists working in the state, four of them located in Dehradun, the state capital. Table 1 shows Dehradun district as more urban and literate population than the mean for India, but with indicators showing greater structural gender inequality that disadvantages women, revealed in uneven measures of sex ratios (ratio of male to female babies at birth) and the gender literacy gap.

**Table 1.** Socio-demographic profile of the study district, with state-level and national comparison data

INSERT TABLE 1 near here (in Tables document)

The project was implemented by Z, a partnership project which works broadly in community mental health promotion and health system strengthening, led by the local non-profit YY organisation and written up as a case study A FULL CASE STUDY PAPER HAS BEEN REMOVED FOR BLINDING. Z works in four communities of Dehradun district with a target population of 100,000 people. In each community five employed team members work with volunteer community members working to promote mental health by through increased knowledge, safe social spaces and partnerships for action (Campbell and Burgess 2012, Mathias 2016) and by strengthening the public mental health system. Over the first four years, 950 PPSD were registered in the programme.

### ***The team***

An eight-member expert by experience (EBE) group was formed and included caregivers as well as people with lived experience of mental illness. Co-author KK was an EBE group member and also works for Z as a team leader.

Participants were offered a small payment for their contribution. The EBE group worked collaboratively in co-production with the research team comprised of XX, a New Zealand public health physician who has lived in India for two decades, PP, a Dehradun based health professional, RR, an Indian-origin social

work academic based in Scotland, and GG, an Indian public health professional living in South India. The profile of people represented in the EBE group is provided in Table Two.

**Table 2.** Profile of experts by experience group members

Insert Table 2. Near here (in Tables document)

***Initiating and agreeing upon the recovery tool development process***

The idea of developing a pictorial recovery tool was initiated by RR, XX and the Z team in reviewing tools developed in high-income countries (HIC) that were not easy to use for people with low literacy, and that did not adequately connect with the context and experiences of PPSD and carers in Dehradun and REFERENCES REMOVED FOR BLINDING. The research team (PP, XX, RR and GG) elected to use a participatory action research framework that built on a health systems strengthening framework, hoping to use a process of ‘empowering co-investigation’ in the participation continuum outlined by Chung and Lounsbury p2131(Chung and Lounsbury 2006) (Gillard, Simons et al. 2012). All participants gave informed consent. The study was approved by the Z Institutional Ethics Committee in January 2017.

**Results**

The results are presented in three sections corresponding to the study aims.

Firstly, an in-depth discussion of the **process** for developing the key domains of the Swasthya Labh Saadan recovery tool (literally ‘health benefit tool’) (SLS

tool), secondly, **summarising** the eight domains identified for the SLS tool and thirdly, **critically reflecting** on the tools' acceptability, process and output.

***Process of developing the key domains of the Swasthya Labh Saadhan (SLS) tool***

To develop domains of recovery the EBE first held two full day workshops and then held six shorter meetings. Participatory methods including telling stories of recovery, discussing photographs, drawing pictures, and discussing pictures drawn, collecting symbols, focus group discussions and participant observation to generate key domains of recovery. In-depth interviews were also held with EBE participants. Key terms agreed upon included: *swasthya labh saadhan* (recovery tool for health), *theek hona* (to be well) and *swastha rehna* (remain in good health). Triangulation, using a process of review, analysis and comparison of the diverse forms of data collected, verified and strengthened the findings.

Figure One demonstrates the co-production process, building on the spiral process of PAR p 13 (Loewenson, Laurell et al. 2014).

**INSERT NEAR HERE**

**Figure 1.** Flow chart of the tool development and analysis process

***Data analysis***

EBE members and researchers used the generated data to analyse and develop domains of the SLS recovery tool following a framework described by Gillard et al (Gillard, Simons et al. 2012).

### ***Stage 1 – Preliminary analysis***

EBE members generate concepts of recovery by discussing facets of recovery for themselves, their household or in their community then grouping concepts to describe key areas for recovery.

### ***Stage 2 – Developing an initial domain framework***

The group proposed a framework of broad ‘domains’ of recovery, within which practical activities for PPSD and caregivers would be detailed. After the second EBE meetings XX and PP reviewed the data generated in Stage 1 to condense the themes into seven preliminary domains.

### ***Stage 3 – Probing the domains***

In the third EBE meeting there was a lengthy discussion of proposed domains and the domain of “Engaging spiritually” was added while two other domain names were changed to better reflect nuances of group generated data.

### ***Stage 4 - Defining each domain’s framework in pictorial form***

EBE members proposed four or more activities related to each domain which were illustrated with line drawings by the artist, a fourteen-year-old student studying in Dehradun district. Pictures were reviewed by EBE members to

assess their cultural appropriateness, comprehensibility and generalisability and revised in response to feedback. Examples of EBE feedback are provided below:

*“The woman depicted is peeling onions, but she is kneeling with her legs underneath her, which suggests she is praying. It would be better to have her squatting.”*

*“The picture of the child going to school shows the child carrying the backpack. Her father should be carrying the school bag.”*

### ***Stage 5 – Piloting the domains and refining the tool***

The final tool format was developed by PP and XX, in discussion with EBE members and comprised of an A4 sized plastic folder with paper sheets, which portrayed the eight domains in pictorial form. A client and community team member could select their preferred activities for recovery for the ensuing fortnight. Pictures could be cut-out and pasted into their own activity folder and reviewed by the community worker, client and caregiver two weeks later.

Preliminary piloting of the tool suggested it was acceptable, easy to understand, used primarily by PPSD directly, and practically useful. A further adaptation suggested by an EBE was that coloured pencils and colouring in the pictures could enhance tool engagement.

### ***Stage 6 – Thematic analysis of transcripts***

In-depth analysis of transcripts (EBE workshops and in-depth interviews) to understand concepts by XX and RR involved reading and re-reading transcripts to seek consistent patterns inherent in the data, and critical reflection. These were summarised into three meta-themes.

### ***Critical reflection***

Group members were initially resistant to the idea that they had any expertise or knowledge to offer and as described below

*“We are not experts of any kind. We are just people who have so many problems in our families and we are trying to find a way to get by. You people, (from Z) are the ones who are the experts, so it is you who should be telling about this project and our SLS work we have been doing together. You are the ones who have guided us all.”*

Early in the process XX, RR and PP submitted an abstract about the SLS tool for a conference, yet had not thought to discuss the abstract development and submission process with the whole group. Six weeks later when the abstract was accepted for presentation, the researcher team critically reflected to recognise that this process was not jointly developed. The researcher team apologised for their non-collaborative conference application process, which was discussed with the EBE group. We queried whether any EBE members would be interested to participate or to co-present with a pre-made video or a Skype link however the group responded with “It is our tool but it’s your project and your



*rozi roti*” (daily bread) i.e. that the SLS tool belonged to the EBE group, the researcher team and the community but the public and paid presentations of the collaborative work could be done by the researchers.

***The components of the Swasthya Labh Saadhan recovery tool***

The eight domains developed and agreed upon in the EBE group, with the underlying concepts and verbatim quotes, are presented in Table 3 with a further analysis of these themes by the researcher team, into three meta-domains of normalcy, belonging and contributing.

**Table 3.** Eight domains developed through co-production process, with supporting quotes and actions

INSERT TABLE 3 NEAR HERE

An example of the pictorial nature of the tool is shown in the line drawings used for the domain titled ‘Having fun’ in Figure Two. **INSERT Figure Two near here.**

**Figure Two.** The domain titled ‘Having fun’ (maza karna) and associated pictures in SLS

Thematic analysis of all the transcripts by two of the researchers, XX and RR, demonstrated a prevalent construct of mental health as primarily social and

cultural (versus biomedical). This analysis distilled three key ways that a PPSD and their household engages with the domains described below:

***Recovery is achieved and evident through activity***

Being busy and active was repeatedly described as a marker of wellness and as a pathway to recovery. Four of the domains described above include components of being engaged in different ways. An example of 'Being spiritually engaged' was supported by an illustration that showed someone ringing a temple bell while 'Being an active family member was illustrated by a family sitting and eating a meal together. 'Being an active community member' was exemplified by a picture of a man going to mosque at communal prayer time. Furthermore, community members identified actions as the most practical way to start a recovery journey. Participants described the benefits of activity as distraction from emotional difficulties and as providing a sense of achievement:

*GM5: Well I get a little bit of peace. I wash up and bathe. I do rituals and take grandchildren to school.*

*GM3: In such times, we forget our troubles, right?*

*GM5: Yeah.. a little bit. I cook and knit a little. ( ) then my mind does not wander here and there.*

FGD 3

Activity in the early morning brought a sense of inner peace and was important for wellbeing as well as fitting with gendered societal expectations for women to rise early for purposeful (sweeping) or less purposeful (devotional practice) types of activities.

*I feel good when I get up a little early in the morning. I feel peace early in the morning. Sometimes I feel good reading a book. Going out somewhere and speaking to someone good. Doing rituals and fasting feels good sometimes.*

GM1, FGD2

### ***Recovery is supported by the physical environment***

Participants underlined the importance of their physical environment for recovery. Access to quality housing, space for cooking, and play areas were described as important for being mentally healthy.

*No one should ever think that they should stay far from a sick person. The environment at home and in the neighbourhood should be good.*

GM2, FGD3

### ***Recovery is supported by economic and social resources***

Participants described mental distress because of the lack of employment and low income, and shared their aspirations for a better life:

*I have a lot of problems. All my life I have had only troubles and difficulties. (...) Other people go to work. I keep running behind work. Everybody gets work, only I don't. (...) I want to be like the other women I see, have money and buy whatever they feel like. I also want to do that. (...) I have been trying to get a job that will pay better. (...) I feel overcome by these troubles, and then I also have an alcoholic husband, and the place where I stay is not good.*

GM 4, FGD 1

In describing their efforts to find employment, EBE members outlined how they navigate between hope, hard work and despair:

*I feel that hard work is all we have. We have to keep our spirits up, keep believing in our heart, and do not commit suicide. Still, I do think about suicide sometimes.*

GM4 FGD1

Social resources, and specifically social inclusion was described as a key factor impacting participation and social engagement. The participant below described how community members consider mental illness as contagious:

*Nowadays the situation is that people see each other and get irritated. They say that this person is sick so stay far away, or we will also get sick.*

*But people don't realize that anyone can get sick at any time. (..). No one should ever think that they should stay far from a sick person.*

GM2, FGD3

The way these themes interact the meta-domains is summarised in Table 4.

**Table 4.** Matrix table showing how the meta-domains interact with the meta themes

The domains identified in the SLS as a co-produced tool were acceptable and legitimate for the team who participated in co-producing this resource. The acceptability and legitimacy is examined in a further study (currently being written up) where this research team evaluates the tool in a pilot study of 26 PPSD.

## **Discussion**

Using a framework of participatory action research to co-produce a recovery tool, this study shows ways in which a group of community members with lived experience of psycho-social disability were involved in knowledge production.

***How does the 'Swasthya Labh Saadhan' (SLS) recovery tool compare with recovery tools from high-income countries?***

Several domains of SLS map directly or indirectly onto recovery domains in tools developed in HIC. 'Household responsibilities', 'self-care', 'reducing addictive behaviour' and 'social networks' also feature in the Recovery Star tool

(MacKeith, Burns et al. 2010). The Canadian tool “Do – Live – Well” (Moll, Gewurtz et al. 2015) also includes self-care’, ‘connecting with others’, ‘experiencing pleasure and joy’ and ‘contributing to community and society’. Using a similar approach to the Wellness Recovery Action Planning (WRAP) tool, SLS proposes that a PPSD identify new actions that may increase mental wellness from recovery domains similar to the “Wellness Toolbox” to build into daily rhythms (Copeland 2002).

Differing from HIC recovery frameworks, this tool uses a visual approach to recovery which increases the tool accessibility in a setting where there is low literacy and education. Use of pictures or pictographs has been found to enhance recall and engagement with health related tools in low literacy settings (Houts, Bachrach et al. 1998). The domains generated in this tool provide a strong focus on the **role** of the PPSD such as ‘Being a friend’ or ‘Being an active family member’ reflecting the relational understanding of mental wellbeing prevalent in South Asia(White 2010). SLS also gives greater attention to one’s role within a household and a community, (the domains ‘Being an active family member’, ‘Contributing to the household’ and ‘Being an active community member’). Themes of productive activity and skills for community participation, were similarly found in a recent study in India assessing caregiver priorities for recovery (Janardhana, Raghevendra et al. 2018). The domain of spiritual engagement has not been a feature in most recovery tools developed in

HIC but was regarded as a core component by the EBE group in the North Indian context, which was also described in another Indian study (Raguram, Venkateswaran et al. 2002). Notably absent in the eight domains of this tool is any mention or expectation of access to care, medicines or social or health services that would support recovery. This seems likely to reflect a context with almost no accessible mental health services, or medicines, or community-based services, suggesting that these supports to recovery were not imagined or expected.

These findings of convergent and divergent components between our tool and existing HIC tools reflects societal and psycho-social contexts and was also described in another study which compared concepts of recovery held by PPSD in Chennai and Perth (Gopal and Henderson 2015). The substantive value of our approach lies in the co-production process that we have taken which seeks to embody local concerns and understandings (Kohrt, Mendenhall et al. 2016). This process builds on a community mental health competencies approach (Campbell and Burgess 2012), where community members have experiential knowledge developed within a safe social space, and in collaboration with partners of a local organisation, to develop a contextually valid recovery tool (Campbell and Burgess 2012, Mathias 2016). We would expect the SLS to contribute to greater utility and effectiveness in the implementation phase. This user-led approach has been critical for the development of recovery movements

in locations as diverse as Scotland and Hong Kong (Bradstreet and McBrierty 2012, Slade, Leamy et al. 2012)

***How did coproduction impact the form and process of the research?***

By using a participatory process generating knowledge with an EBE group, this study can critique the dominant discourse, where knowledge production relies on a subject expert who has acquired knowledge through academic qualifications and study (Chung and Lounsbury 2006). For the EBE group, there was a growing realisation of the implicit knowledge that they could offer as they participated in knowledge co-production. For example, the seemingly amorphous data of pictures, stories and symbols generated by the group was transformed through analysis and discussion into the eight domains. For the researcher group, who believed we were using empowering approaches, we were surprised to become aware we had inadvertently made several uni-lateral decisions (e.g. in submitting a conference abstract). This challenge was surprising and uncomfortable.

The other key contribution of a co-productive process with the EBE was in underscoring the centrality of activity, the physical environment, and social and economic resources for recovery. The critical role of mental health determinants has been well described yet steps to address the physical, social and economic environment are not strong in other recovery tools. “A focus on social justice may provide an important corrective to what has been seen as a growing over-



emphasis on individual pathology. Mental health is produced socially: the presence or absence of mental health is above all a social indicator and therefore requires social, as well as individual solutions” p5, (Friedli and Organization 2009).

### **Challenges to enabling emancipatory participatory action research?**

The SLS tool development used an engaged and participatory process that was dynamic, but did not fully accomplish the goal of emancipatory PAR which seeks to develop ‘egalitarian partnerships with community members that equalize decision making power between researchers and community members’ (pg 2131, (Chung and Lounsbury 2006). The researcher team represented the joint work by sending a conference abstract and made decisions about the SLS implementation processes without consultation with the EBE group. Difficulties in making the research process fully participatory and emancipatory included EBE participants recognising themselves as expert. The term ‘experts by experiences’ originates from high income settings with ‘services’ that are ‘expert driven’. The EBE term is perhaps a reaction in part to the nature of vertical hierarchies where traditionally professional health providers are regarded as experts. However despite the lack of mental health services in India, it is likely to be relevant in the Indian context, given the top down nature of biomedical services (Jain 2016). In this context ‘patients’ however, might instead be conceptualizing themselves in different ways as suggested by an EBE

group member ‘just people ...trying to find a way’. The concept that being a ‘patient’ might be constructed by biomedical service providers has been discussed with respect to people with little access to services in Guatemala (Harvey 2008) and seems useful to consider with respect to forms of participation in this Indian context.

An additional challenge to participation was related to literacy and education meaning illiterate group members initially contributed less in discussions. Furthermore, the majority of EBE members had had no prior politicisation, contact with any user movement and had limited literacy and education, perhaps led to them feeling unqualified to own the process or challenge its power relations.

Additionally, as a first ‘experiment’ with both co-production and PAR, there was a developing consciousness in both the EBE and the research team about what constituted participation, with the processes evolving en route. The EBE understanding that the tool was theirs, but that the research and Z team could use it to generate their ‘daily bread’ illustrates this well. The actual process was closer to engaged co-production (knowledge production) and the timelines did not permit (or we did not allow them to permit) genuine and deep engagement in power relations, although it was dynamic and moved with time (Chung and Lounsbury 2006). We identified key points in the tool development process at which co-ownership could be enhanced. These include early and explicit

discussions about how the process could be co-owned, what each group's expectations and hopes were, and identifying key junctures where critically reflective discussion could be held.

***What are the implications for policy and practice from this study?***

This study has several key implications for mental health policy and practice in India, and for future directions of global mental health more broadly. Firstly, it suggests that people with lived experience of mental health difficulties have sophisticated and diverse understandings of what recovery means to them.

Mental health programmes should prioritise involving community members with lived experience of mental health difficulties in designing mental health promotion, programmes and policies, and resources and seek to use participatory approaches at national, state, district, organisational and community levels.

Employing an honest and critically reflective process can also ensure that participation is genuine so that programmes and policies benefit from local knowledge.

Secondly, use of a co-developed mental health recovery tool in this study generated local conversations around recovery that expanded horizons for all participants. Training lay and professional mental health workers to engage in co-productive and participatory ways helps knowledge flow from bottom-to-top which can enhance trust with communities and provide avenues to improve

mental health care delivery. Thirdly, a participatory methodology ensures that the grass-root experiences of participants in a disadvantaged environment, conceptualise mental health as both a social and a medical concern, requiring both social and medical policy responses. The meta-themes of this study underline the importance of psycho-social interventions that address behavioural activation (keeping busy)(Patel, Belkin et al. 2012), and addressing macro determinants of health including the physical, social and economic environment such as housing, employment and gender equality (Kirmayer and Pedersen 2014, Patel, Parikh et al. 2015). Fourthly, the SLS tool provides a framework where the recovery approach can be taught and practically used in engagement with PPSD, who are or are not literate, by psychiatrists, nurses, caregivers, community workers and others implementing the National mental health programme and policy in India(Government of India 1982).

Implementation research that examines ways this and other co-produced tools could be used practically in training, community -based rehabilitation as well as in development of policy and programmes is needed.

Fifthly, this tool could potentially open new spaces and connections for people across social boundaries such as empowering women with PSD to engage in new activities outside of established gender roles; and this could be an overt focus with community workers enabling such processes. Another area of potential development could be in addressing recovery from the impacts of

multiple marginalities. For example, a woman from an oppressed caste with a mental health problem may experience the benefits of greater social participation and increased mental health also impacting on other sources of marginality and more community/social connections potentially re-shaping power relationships. These hypotheses require further research to examine the impact of locally contextualized approaches to recovery on social power and marginality.

### ***Methodological considerations***

Methodological weaknesses in this study include under-representation of men and people from a Muslim faith tradition in the EBE group and insufficient time for deep, power-shared participation. We incorporated four strategies to address the trustworthiness of the findings of this study (Lincoln & Guba, 1985): credibility, transferability, dependability and confirmability. Triangulation by using different sites and analyses by authors with different ethnic backgrounds increased the study's credibility. Dependability and confirmability of study results were increased with rich, extensive group discussions and individual interviews with PPSD's and carers, and with incorporation of feedback on tool utilization with pilot testing. We provided detailed contextual information to maximise transferability, in particular, to urban and peri-urban settings in Hindi-speaking North India. We acknowledge that the transferability of the tool

domains should be evaluated critically in different contexts with different languages and cultural contexts, such as in rural North East India.

### **Summary**

Mental health recovery tools and approaches have been dominated by Western frameworks and values, and there is an urgent need for contextualised tools to support recovery among people living in low and middle-income countries. This paper outlines the process used to co-produce a recovery tool, *Swasthya Labh Sadhan*, and the key domains of that tool, in the context of peri-urban North India. The eight key domains outlined in the SLS tool can provide a clear framework for lay and professional community workers in South Asia, to support rehabilitation and recovery among people with mental health problems. The pictorial nature of the tool is particularly helpful for people with low literacy. The three meta-domains identified as central to recovery were normalcy, belonging and contributing. Mental health programmes at policy, organisational and family levels should prioritise involving people with lived experience of mental health difficulties in designing mental health programmes and policies, and use a critically reflective process to ensure that it is participatory. Working with lay and professional health workers in co-productive and participatory ways will enhance trust with communities and strengthen mental health systems and delivery of care.

## References

- Agarwal, V. and S. Sinha (2016). "Recovery in child and adolescent mental health: a new approach." Journal for Indian Association of Child and Adolescent mental health **12**(2): 116-120.
- Aldersey, H. M., A. B. Adeponle and R. Whitley (2017). Diverse approaches to recovery from severe mental illness. The Palgrave Handbook of Sociocultural Perspectives on Global Mental Health. J. S. White R., Orr D., Read U. , Springer: 109-127.
- Anthony, W. A. (1993). "Recovery from mental illness: The guiding vision of the mental health service system in the 1990s." Psychosocial rehabilitation journal **16**(4): 11.
- Bayetti, C., S. Jadhav and S. Jain (2016). "The Re-covering Self: a critique of the recovery-based approach in India's mental health care." Disability and the Global South **3**(1): 889-909.
- Bradstreet, S. and R. McBrierty (2012). "Recovery in Scotland: beyond service development." International review of psychiatry **24**(1).
- Campbell, C. and R. Burgess (2012). "The role of communities in advancing the goals of the Movement for Global Mental Health." Transcultural Psychiatry **49**(3-4): 379-395.
- Chaturvedi, S. K. and J. Thirthalli (2015). "Recovery oriented services: should we move from evidence-based practice to value-based practice?" Psychosocial rehabilitation and mental health journal **2**(1).
- Chung, K. and D. W. Lounsbury (2006). "The role of power, process, and relationships in participatory research for statewide HIV/AIDS programming." Social Science & Medicine **63**(8): 2129-2140.
- Cook, J. A., M. E. Copeland, L. Corey, E. Buffington, J. A. Jonikas, L. C. Curtis, D. D. Grey and W. H. Nichols (2010). "Developing the evidence base for peer-led services: Changes among participants following Wellness Recovery Action Planning (WRAP) education in two statewide initiatives." Psychiatric Rehabilitation Journal **34**(2): 113.
- Copeland, M. E. (2002). "Wellness Recovery Action Plan." Occupational Therapy in Mental Health **17**(3-4): 127-150.
- Friedli, L. and W. H. Organization (2009). "Mental health, resilience and inequalities."
- Gillard, S., L. Simons, K. Turner, M. Lucock and C. Edwards (2012). "Patient and public involvement in the coproduction of knowledge: reflection on the analysis of qualitative data in a mental health study." Qualitative Health Research **22**(8): 1126-1137.
- Gopal, S. and A. R. Henderson (2015). "Trans-cultural study of recovery from severe enduring mental illness in Chennai, India and Perth, Western Australia." Journal of Psychosocial Rehabilitation and Mental Health **2**(1): 51-57.
- Government of India (1982). National mental health programme for India. New Delhi, Department of Health and Family welfare.
- Greenhalgh, T. (2009). "Chronic illness: beyond the expert patient." BMJ: British Medical Journal **338**(7695): 629-631.
- Harvey, T. S. (2008). "Where There is no Patient: An Anthropological Treatment of a Biomedical Category." Culture, Medicine, and Psychiatry **32**(4): 577.
- Houts, P. S., R. Bachrach, J. T. Witmer, C. A. Tringali, J. A. Bucher and R. A. Localio (1998). "Using pictographs to enhance recall of spoken medical instructions." Patient Education and Counseling **35**(2): 83-88.
- Jadhav, S. (2013). "Challenges of teaching clinically applied anthropology and cultural psychiatry in India: an evolving partnership between a UK university and an Indian NGO." Teaching Anthropology **2**(2): 3-14.
- Jadhav, S., D. Mosse and N. Dostaler (2016). "Minds of caste—Discrimination and its affects." Anthropology Today **32**(1): 1-2.
- Jain, S. (2016). "Cross-cultural psychiatry and the user/survivor movement in the context of global mental health." Philosophy, Psychiatry, & Psychology **23**(3): 305-308.
- Jain, S. and S. Jadhav (2008). "A cultural critique of community psychiatry in India." International Journal of Health Services **38**(3): 561-584.

Jain, S. and D. Orr (2016). "Ethnographic perspectives on global mental health." Transcultural Psychiatry **53**(6): 685-695.

Janardhana, N., G. Raghevendra, D. Naidu, L. Prasanna and T. Chenappa (2018). "Caregiver perspective and understanding on road to recovery." Journal of Psychosocial Rehabilitation and Mental Health **5**: 43-51.

Kirmayer, L. J. and D. Pedersen (2014). "Toward a new architecture for global mental health." Transcultural psychiatry **51**(6): 759-776.

Kohrt, B. A., E. Mendenhall and P. J. Brown (2016). "How anthropological theory and methods can advance global mental health." The lancet. Psychiatry **3**(5): 396.

Lancet Global Mental Health group (2007). "Scale up services for mental disorders: a call for action." Lancet DOI:10.1016/S0140-6736(07)61242-2.

Lloyd, F., S. Jain and B. Davar (2016). What does 'recovery' mean in an urban Indian slum context? Annual Conference of the Association of Social Anthropologists, July 2016. Durham.

Loewenson, R., A. C. Laurell, C. Hogstedt, L. D'Ambruso and Z. Shroff (2014). Participatory action research in health systems: a methods reader, Regional Network for Equity in Health in East and Southern Africa (EQUINET) in association with Training and Research Support Centre (TARSC), Alliance for Health Policy and Systems Research (AHPSR), World Health Organization (WHO) and the International Development Research Centre (IDRC) Canada.

MacKeith, J., S. Burns, E. Facey and J. Johnson (2010). Mental Health Recovery Star: Organisational Guide, Mental Health Providers Forum.

Mathias, K. (2016). Shadows and light - examining community mental health competence in North India. PhD, Umea Universitet.

Mehrotra, N. (2012). "Disability, Gender and Caste: Marginality, Exclusion and Opportunities in Indian Economy." Women's Link **18**(2): 5-8.

Ministry of social justice and empowerment (2018). Annual report 2017-8. New Delhi, India, Ministry of social justice and empowerment.

Moll, S. E., R. E. Gewurtz, T. M. Krupa, M. C. Law, N. Lariviere and M. Levasseur (2015). "'Do-Live-Well': a Canadian framework for promoting occupation, health, and well-being." Can J Occup Ther **82**(1): 9-23.

Mueser, K., P. Corrigan, D. Hilton and et al (2002). "Illness management and recovery: a review of the research." Psychiatr Serv **53**: 1272-1284.

Nayar, K. R. (2007). "Social exclusion, caste & health: a review based on the social determinants framework." Indian J Med Res **126**(4): 355-363.

Ottmann, G., C. Laragy, J. Allen and P. Feldman (2011). "Coproduction in Practice: Participatory Action Research to Develop a Model of Community Aged Care." Systemic Practice and Action Research **24**(5): 413-427.

Patel, V., G. S. Belkin, A. Chockalingam, J. Cooper and S. Saxena (2012). "Grand Challenges: Integrating Mental Health Services into Priority Health Care Platforms." PLoS Med **10**(5): e1001448.

Patel, V., S. Chatterji and D. Chisholm (2011). "Chronic diseases and injuries in India." Lancet **377**: 413-428.

Patel, V., R. Parikh, S. Nandraj, P. Balasubramaniam, K. Narayan, V. K. Paul, A. S. Kumar, M. Chatterjee and K. S. Reddy (2015). "Assuring health coverage for all in India." The Lancet **386**(10011): 2422-2435.

Raguram, R., A. Venkateswaran, J. Ramakrishna and M. G. Weiss (2002). "Traditional community resources for mental health: a report of temple healing from India." BMJ **325**(7354): 38-40.

Roberts, G. and J. Boardman (2013). "Understanding 'recovery'." Advances in psychiatric treatment **19**(6): 400-409.

Ruggeri, M. and M. Tansella (2013). "Psychosocial intervention trials: another challenge in measuring complexity." Epidemiology and Psychiatric Sciences **22**(2): 101-103.

Shidhaye, R. and M. Kermode (2013). "Stigma and discrimination as a barrier to mental health service utilization in India." International Health **5**(1): 6-8.



Slade, M., M. Amering, M. Farkas, B. Hamilton, M. O'Hagan, G. Panther, R. Perkins, G. Shepherd, S. Tse and R. Whitley (2014). "Uses and abuses of recovery: implementing recovery-oriented practices in mental health systems." World Psychiatry **13**(1): 12-20.

Slade, M., M. Leamy, F. Bacon, M. Janosik, C. Le Boutillier, J. Williams and V. Bird (2012). "International differences in understanding recovery: systematic review." Epidemiology and Psychiatric Sciences **21**(4): 353-364.

White, S. C. (2010). "Analysing wellbeing: a framework for development practice." Development in Practice **20**(2): 158-172.

World Health Organisation (2011). Mental health atlas 2011. Geneva, WHO.

World Health Organisation (2016). mhGAP intervention guide for mental, neurological and substance abuse disorders in non-specialized health settings Version 2.0. S. Saxena. Geneva, Switzerland, WHO.